## NDS Common Data Elements Summary of Core Recommendations: Headache CDEs

## Subgroup:

**Headache CDEs** 

### **Recommendations:**

These instruments and elements are recommended for use in all Headache studies:

### **Core Instruments:**

- 1. Functional Disability Inventory (FDI)-Child and Adolescent Form
- 2. Functional Disability Inventory (FDI)-Parent Form
- 3. Headache Impact Test-6 (HIT-6)
- 4. Migraine Specific Quality of Life Questionnaire (MSQoL)
- 5. Pediatric Migraine Disability Assessment (PedMIDAS)
- 6. Headache Diary

### **Core Elements:**

| Sub-Domain    | Data Element                               | CDE ID<br>(Internal use only) |
|---------------|--|-------------------------------|
| Demographics  | Birth date                                 | C00007                        |
| Demographics  | Age value                                  | C00007                        |
| Demographics  | Ethnicity USA category                     | C00008                        |
| Demographics  | Race USA category                          | C00020                        |
| Ŭ .           | <u> </u>                                   |                               |
| Demographics  | Gender Type                                | C00035                        |
| Social Status | Education level USA type                   | C00012                        |
| Social Status | Education year count                       | C00015                        |
| Social Status | Employment status                          | C00204                        |
| Social Status | Family income range                        | C00205                        |
| Social Status | Family income supported persons count      | C00206                        |
| Social Status | Marital or partner status                  | C00207                        |
| Social Status | Military USA service branch type           | C00208                        |
| Social Status | Military combat zone deployment number     | C00209                        |
| Social Status | Military combat status                     | C00210                        |
| Social Status | Living with persons count                  | C00214                        |
| Social Status | Living with person relationship type       | C00215                        |
| Social Status | Military USA rank category                 | C00220                        |
| Social Status | Military service status                    | C00221                        |
| Social Status | Job classification category                | C00222                        |
| Social Status | Health insurance type                      | C00226                        |
| Social Status | School repeat grade indicator              | C14117                        |
| Social Status | Student course load status                 | C15986                        |
| Social Status | Employment weekly hour count               | C15987                        |
| Social Status | Employment paid job count                  | C15988                        |
| Social Status | Unemployed reason                          | C15989                        |
| Social Status | Military non-combat zone deployment number | C15990                        |



| Sub-Domain             | ary of Core Recommendations: Hea                             | CDE ID<br>(Internal use only) |
|------------------------|--|-------------------------------|
| Social Status          | Deployment most recent start date and time                   | C15991                        |
| Social Status          | Deployment most recent end date and time                     | C15992                        |
| Social Status          | Dependent children number                                    | C15993                        |
| Social Status          | Dependent children living in household number                | C15994                        |
| Social Status          | Household wage earners number                                | C15995                        |
| General Health History | Medical history condition SNOMED CT code                     | C00313                        |
| General Health History | Medical history condition text                               | C00322                        |
| General Health History | Data source  | C08147                        |
| General Health History | Adopted indicator  | C10813                        |
| General Health History | Relative first degree total count                            | C15997                        |
| General Health History | Relative first degree live count                             | C15998                        |
| General Health History | Relative first degree decease count                          | C15999                        |
| General Health History | Relative first degree unknown count                          | C16000                        |
| General Health History | Relative second degree total count                           | C16001                        |
| General Health History | Relative second degree live count                            | C16002                        |
| General Health History | Relative second degree decease count                         | C16003                        |
| General Health History | Relative second-degree unknown count                         | C16004                        |
| General Health History | Data collected date and time                                 | C06005                        |
| General Health History | Pregnant ever indicator                                      | C10556                        |
| General Health History | Birth control method type                                    | C10981                        |
| General Health History | Gravida maternal value                                       | C11065                        |
| General Health History | Pregnancy indicator  | C15624                        |
| General Health History | Birth control indicator                                      | C16008                        |
| General Health History | Birth control last used date and time                        | C16009                        |
| General Health History | Pregnancy confirmed date and time                            | C16011                        |
| General Health History | Pregnancy estimated delivery date ultrasound based indicator | C16013                        |
| General Health History | Pregnancy prenatal testing performed indicator               | C16014                        |
| General Health History | Prenatal testing type  | C16015                        |
| General Health History | Prenatal testing date and time                               | C16016                        |
| General Health History | Prenatal testing result                                      | C16017                        |
| General Health History | Pregnancy complication indicator                             | C16018                        |
| General Health History | Pregnancy infection illness indicator                        | C16020                        |
| General Health History | Pregnancy prior history births full-term count               | C16022                        |
| General Health History | Pregnancy prior history births pre-term count                | C16023                        |



# NINDS Common Data Elements Harmonizing Information. Streamlining research. Summary of Core Recommendations: Headache CDEs

| General Health History | Pregnancy prior history birth defect indicator                        | C16024 |
|------------------------|---|--------|
| General Health History | Pregnancy prior history loss indicator                                | C16026 |
| General Health History | Pregnancy prior history loss week count                               | C16027 |
| General Health History | Pregnancy prior history toxic exposure type                           | C16028 |
| General Health History | Pregnancy estimated delivery date and time                            | C16173 |
| General Health History | Menstrual period last date  | C16175 |
| General Health History | Delivery or pregnancy termination last date and time                  | C10558 |
| General Health History | Delivery mode type  | C11078 |
| General Health History | Neonate delivery route type   | C11079 |
| General Health History | Delivery caesarean timing status                                      | C11081 |
| General Health History | Pregnancy most recent live born infant indicator                      | C16037 |
| General Health History | Pregnancy fetus normal indicator                                      | C16040 |
| General Health History | Delivery induced reason   | C16042 |
| General Health History | Delivery cesarean section reason                                      | C16044 |
| General Health History | Pregnancy labor delivery complication indicator                       | C16046 |
| General Health History | Tocolytic agents required during preterm labor indicator              | C16048 |
| General Health History | Birth child date and time   | C16049 |
| General Health History | Phenotypic sex child type   | C16050 |
| General Health History | Birth weight child value  | C16051 |
| General Health History | Birth length child value  | C16053 |
| General Health History | Full term delivery child indicator                                    | C16055 |
| General Health History | Gestational age child value   | C16056 |
| General Health History | Activity pulse grimace appearance respiration five minute child score | C16057 |
| General Health History | Activity pulse grimace appearance respiration ten minute child score  | C16058 |
| General Health History | Weight delivery mother measurement                                    | C16059 |
| General Health History | Weight delivery mother unit of measure                                | C16060 |
| General Health History | Pregnancy fetal diagnostic test performed indicator                   | C16062 |
| General Health History | Pregnancy fetal diagnostic test date                                  | C16063 |
| General Health History | Pregnancy fetal diagnostic test result                                | C16064 |
| General Health History | Congenital anomaly child indicator                                    | C16065 |
| General Health History | Newborn complication child indicator                                  | C16067 |



| Sub-Domain                          | ry of Core Recommendations: Hea                   | CDE ID<br>(Internal use only) |
|-------------------------------------|---|-------------------------------|
| General Health History              | Placenta umbilical cord abnormality indicator     | C16069                        |
| General Health History              | Pregnancy outcome type                            | C16169                        |
| General Health History              | Delivery induced reason other text                | C18617                        |
| History of Disease/Injury Event     | Headache migraine type                            | C16005                        |
| History of Disease/Injury Event     | Headache migraine diagnosis indicator             | C16010                        |
| History of Disease/Injury Event     | Headache history indicator                        | C15936                        |
| History of Disease/Injury Event     | Headache typical severity type                    | C15937                        |
| History of Disease/Injury Event     | Headache typical level activities affected result | C15939                        |
| History of Disease/Injury Event     | Headache typical associate symptom type           | C15940                        |
| History of Disease/Injury Event     | Headache symptom frequency                        | C15941                        |
| History of Disease/Injury Event     | Headache month average frequency                  | C15942                        |
| Classification                      | Vision (aura) typical symptom type                | C15946                        |
| Classification                      | Skin sensation typical indicator                  | C15947                        |
| Classification                      | Skin sensation frequency                          | C15948                        |
| Classification                      | Headache typical anatomic site                    | C15949                        |
| Classification                      | Headache typical pain type                        | C15950                        |
| Classification                      | Headache short treatment duration                 | C15951                        |
| Classification                      | Headache long treatment duration                  | C15952                        |
| Classification                      | Headache average treatment duration               | C15953                        |
| Classification                      | Headache shortest untreated duration              | C15954                        |
| Classification                      | Headache longest untreated duration               | C15955                        |
| Classification                      | Headache average untreated duration               | C15956                        |
| Classification                      | Headache frequency                                | C15958                        |
| Classification                      | Headache pain walk up stair typical indicator     | C15960                        |
| Classification                      | Headache worse during activity indicator          | C15961                        |
| Classification                      | Headache affect activity level indicator          | C15962                        |
| Classification                      | Headache school function level percentage value   | C15963                        |
| Classification                      | Headache play function level percentage value     | C15964                        |
| Vital Signs and Other Body Measures | Blood pressure diastolic measurement              | C01507                        |
| /ital Signs and Other Body Measures | Height measurement method type                    | C01513                        |
| /ital Signs and Other Body Measures | Height measurement                                | C01522                        |
| /ital Signs and Other Body Measures | Weight measurement                                | C01541                        |
| /ital Signs and Other Body Measures | Weight measurement method type                    | C01546                        |
| Vital Signs and Other Body Measures | Blood pressure measurement position type          | C01553                        |



## NINDS Common Data Elements Harmonizing Information. Streomlining research. Summary of Core Recommendations: Headache CDEs

| Sub-Domain                                   | Data Flament   | CDE ID              |
|--|--|---------------------|
| Sub-Domain                                   | Data Element   | (Internal use only) |
| Vital Signs and Other Body Measures          | Blood pressure systolic measurement  | C01565              |
| Vital Signs and Other Body Measures          | Weight unit of measure   | C01581              |
| Vital Signs and Other Body Measures          | Height unit of measure   | C01582              |
| Vital Signs and Other Body Measures          | Weight percentile value  | C15900              |
| Vital Signs and Other Body Measures          | Height percentile value  | C15901              |
| Vital Signs and Other Body Measures          | Weight to height ratio value   | C15902              |
| Laboratory Tests and                         | Lab specimen collection date and time C017   | C01701              |
| Biospecimens/Biomarkers                      | Lab specimen concention date and time  | 601701              |
| Laboratory Tests and                         | Food last consumed date and time   | C10821              |
| Biospecimens/Biomarkers                      | 1 000 last consumed date and time  | C10021              |
| Laboratory Tests and                         | Last headache current day elapse time  | C15596              |
| Biospecimens/Biomarkers                      | · · ·  | <b>C</b> 13330      |
| Laboratory Tests and                         | Last headache sample collection elapse   | C15599              |
| Biospecimens/Biomarkers                      | time   | <b>C</b> 13333      |
| Laboratory Tests and                         | Headache severity prior sample   | C15604              |
| Biospecimens/Biomarkers                      | collection score   | 013001              |
| Laboratory Tests and                         | Medication history change indicator  | C15607              |
| Biospecimens/Biomarkers                      | The distance of the last of th | 013007              |
| Laboratory Tests and                         | Premenopausal indicator  | C15618              |
| Biospecimens/Biomarkers                      | •  |                     |
| Laboratory Tests and                         | Menstrual cycle day collection time  | C15621              |
| Biospecimens/Biomarkers                      | value  |                     |
| Laboratory Tests and                         | Pregnancy gestational week value   | C15627              |
| Biospecimens/Biomarkers                      | 5 75   |                     |
| Laboratory Tests and                         | Postpartum indicator   | C15629              |
| Biospecimens/Biomarkers                      | '  |                     |
| Laboratory Tests and                         | Postpartum day week value  | C15630              |
| Biospecimens/Biomarkers                      | ,  |                     |
| Laboratory Tests and                         | Premenarchal indicator   | C15632              |
| Biospecimens/Biomarkers                      |  |                     |
| Laboratory Tests and                         | Gene type  | C10844              |
| Biospecimens/Biomarkers                      |  |                     |
| Laboratory Tests and                         | Gene screened indicator  | C10845              |
| Biospecimens/Biomarkers                      |  |                     |
| Laboratory Tests and                         | Gene mutation indicator  | C10846              |
| Biospecimens/Biomarkers                      |  |                     |
| Laboratory Tests and Biospecimens/Biomarkers | Genetic testing performed indicator  | C15520              |
| •  |  |                     |
| Laboratory Tests and Biospecimens/Biomarkers | Headache gene present indicator  | C15522              |
|  |  |                     |
| Laboratory Tests and Biospecimens/Biomarkers | Gene mutation type   | C15539              |
| piospecimens/piomarkers                      | ,,   |                     |



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| Sub-Domain                                      | Data Element   | CDE ID<br>(Internal use only) |
|---|--|-------------------------------|
| Laboratory Tests and<br>Biospecimens/Biomarkers | Gene nucleotide change name                                    | C15545                        |
| Laboratory Tests and<br>Biospecimens/Biomarkers | Gene amino acid change name                                    | C15549                        |
| Laboratory Tests and<br>Biospecimens/Biomarkers | Gene unclassified variant shown indicator                      | C15553                        |
| Laboratory Tests and<br>Biospecimens/Biomarkers | Gene detection method type                                     | C15557                        |
| Drugs   | Medication prior or concomitant use indicator                  | C02002                        |
| Drugs   | Medication prior or concomitant ongoing indicator              | C02003                        |
| Drugs   | Medication prior or concomitant dose                           | C02006                        |
| Drugs   | Medication prior or concomitant end date and time              | C02008                        |
| Drugs   | Medication prior or concomitant dose frequency                 | C02011                        |
| Drugs   | Medication prior or concomitant dose unit of measure UCUM code | C02013                        |
| Drugs   | Medication prior or concomitant name                           | C02014                        |
| Drugs   | Medication prior or concomitant route type                     | C02015                        |
| Drugs   | Medication prior or concomitant start date and time            | C02016                        |
| Drugs   | Medication prior or concomitant dose unit of measure           | C02022                        |
| Drugs   | Medication prior or concomitant indication text                | C02024                        |
| Drugs   | Adverse event track number                                     | C16029                        |
| Drugs   | Headache pain medication after study drug indicator            | C16211                        |
| Patient Reported Outcomes                       | Headache retire bed indicator                                  | C15893                        |
| Patient Reported Outcomes                       | Headache associated symptom type                               | C15897                        |
| Patient Reported Outcomes                       | Headache worst pain anatomic site                              | C15899                        |
| Patient Reported Outcomes                       | Headache or migraine medication taken type                     | C15969                        |
| Patient Reported Outcomes                       | Headache warning symptom indicator                             | C15971                        |
| Patient Reported Outcomes                       | Headache aura symptom type                                     | C15972                        |
| Patient Reported Outcomes                       | Headache aura symptom onset range                              | C15973                        |
| Patient Reported Outcomes                       | Headache post initial study medication time interval value     | C15975                        |



| NINDS Common Data Elements Summary of Core Recommendations: Headache CDEs |  |                     |
|---|--|---------------------|
| Sub-Domain  | Data Element   | CDE ID              |
|   |  | (Internal use only) |
| Patient Reported Outcomes   | Headache post initial study medication date and time | C15976              |
| Patient Reported Outcomes   | Headache end date and time                           | C15977              |
| Patient Reported Outcomes   | Headache re-start date and time                      | C15978              |
| Patient Reported Outcomes   | Headache re-start end date and time                  | C15979              |
| Patient Reported Outcomes   | Headache affected activity type                      | C15980              |
| Patient Reported Outcomes   | Headache pain medication time AM PM indicator        | C18028              |